



CONNECT

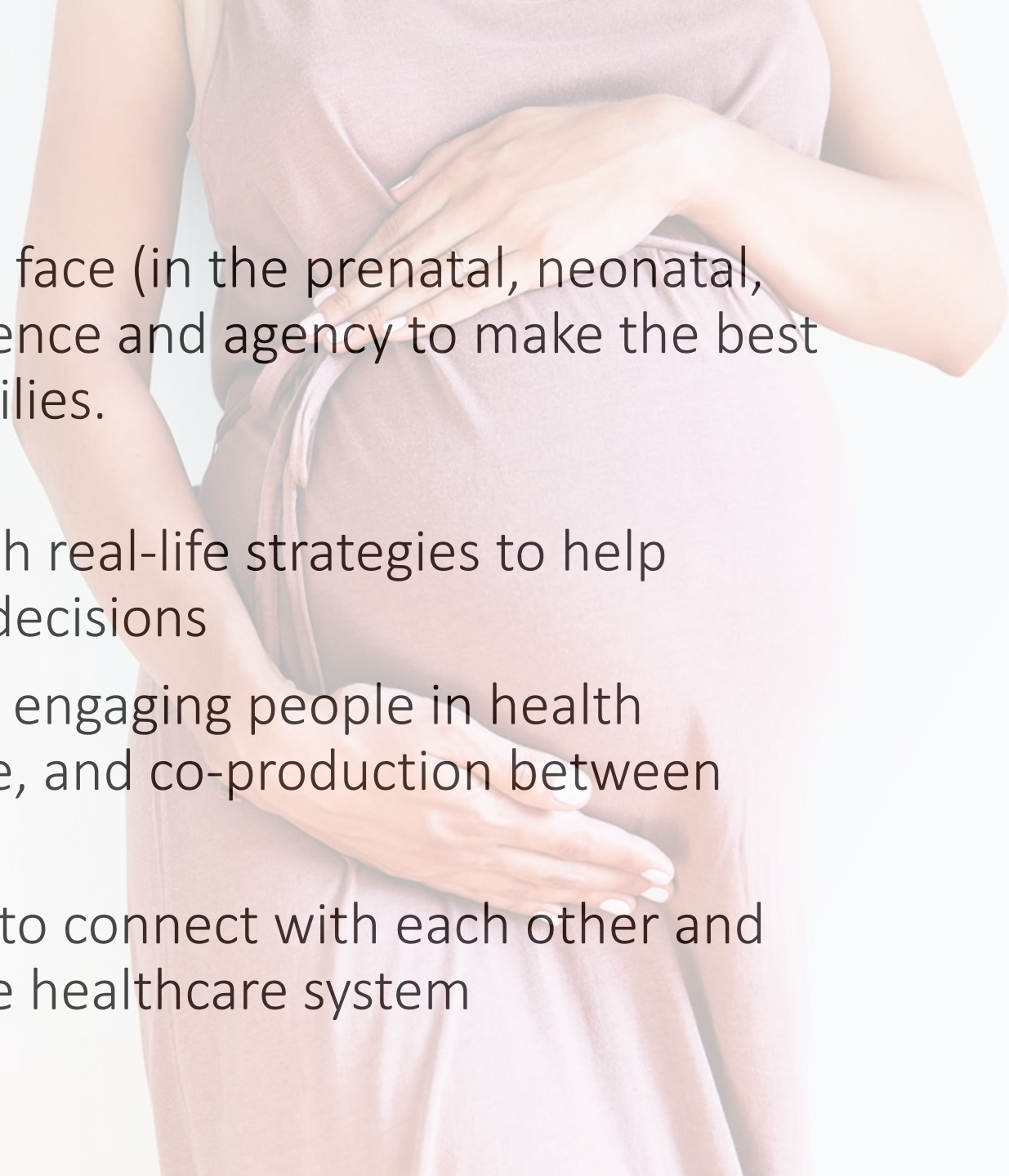
*A Collaborative Work Group
on Newborn Screening and
Congenital Cytomegalovirus*

Natasha Bonhomme | *Founder, Expecting Health*

Mission

Replacing the fear and confusion many face (in the prenatal, neonatal, and early childhood years) with confidence and agency to make the best decisions for themselves and their families.

- Bridge science-based information with real-life strategies to help women and families make informed decisions
- Contribute to cultural change around engaging people in health systems, promoting continuity of care, and co-production between people, providers, and communities
- Provide people with the opportunity to connect with each other and build skills to engage more fully in the healthcare system





CONNECT

Community of Newborn Experts Collaborating Together

A Collaborative Work Group

Connecting.

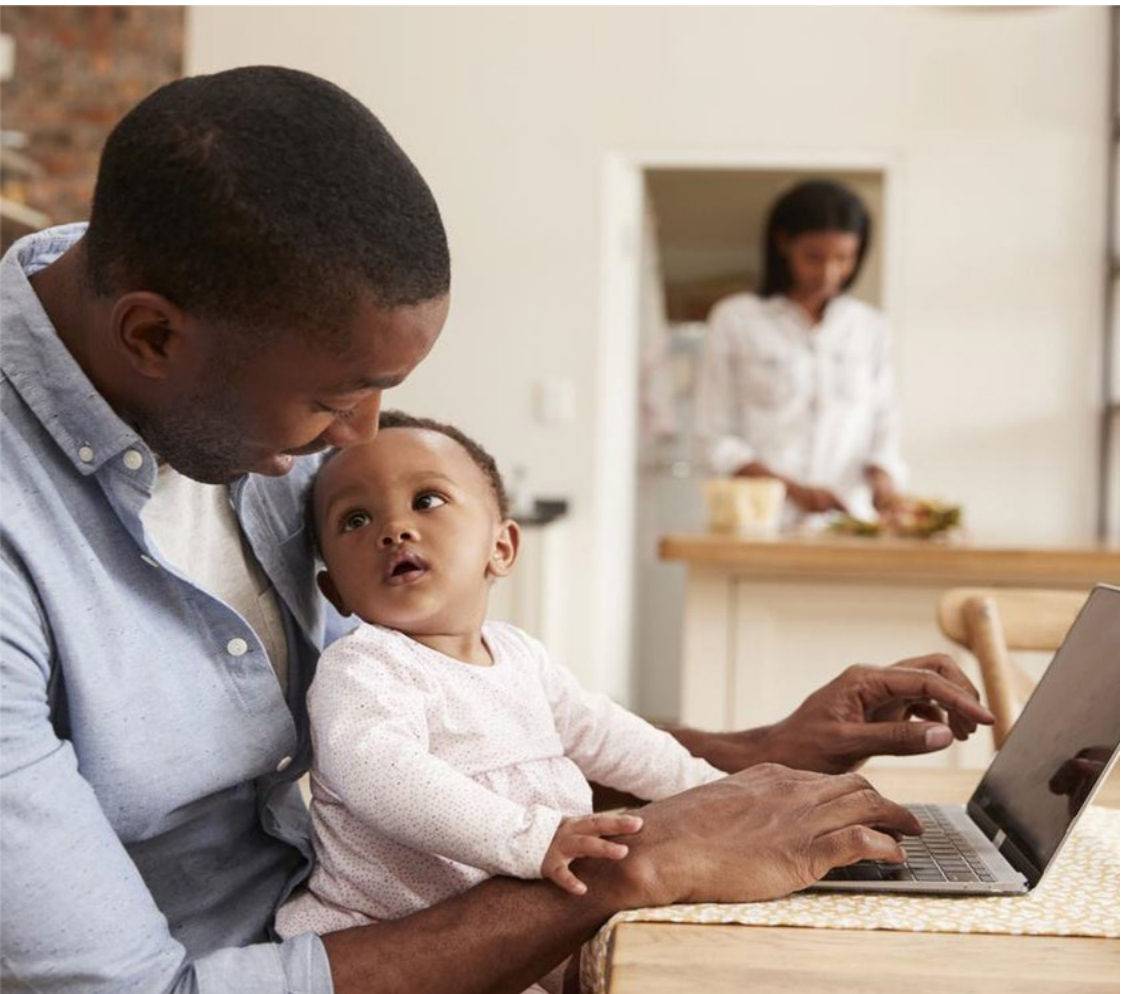
Sharing.

Building.

In March 2022, Expecting Health launched a collaborative workgroup to bring together congenital cytomegalovirus and newborn screening experts and stakeholders to connect, share perspectives, and build a foundation for collaboration.

How can we work together to break silos, develop strategies, and improve cCMV and newborn screening initiatives?





Virtual meetings using Zoom



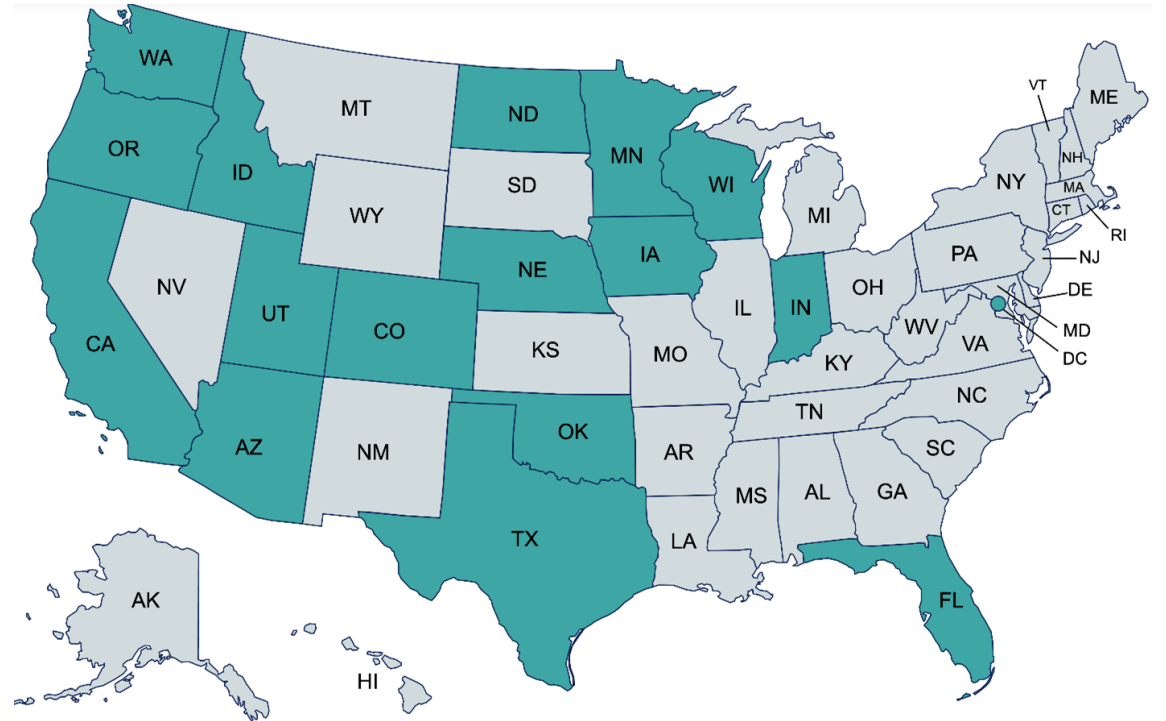
1.5 hours long



Presentations followed by structured discussion and strategy sessions

Work Group Members

- Parents
- State NBS Laboratories
- State NBS Follow-Up Programs
- cCMV and EHDI Programs
- Industry Representatives
- Healthcare Providers
- Professional Organizations
- Advocacy Organizations
- Researchers





First Meeting Recap
March 3, 2022



Presentation and Discussion

- Khaliah Flemming and Amanda Devereaux from the National CMV Foundation presented on CMV patient and family experiences
- Work Group participants had a conversation about what a successful collaboration around cCMV and NBS looks like and the results they would like to see from this collaboration



A background image showing several hands of different skin tones gently holding a globe of the Earth. The hands are positioned around the globe, with fingers and palms visible, suggesting a sense of global unity and care. The image is slightly blurred and has a soft, warm color palette.

Second Meeting Recap

June 29, 2022



cCMV Testing in Utah

Stephanie Browning McVicar, Au.D., CCC-A

Early Hearing Detection & Intervention (EHDI)
CMV Public Education and Testing
Children's Hearing Aid Program



Minnesota Congenital Cytomegalovirus Screening

Sondra Rosendahl, MS, LCGC

Group Discussion

- **Question 1: What support and resources do states/programs need as they begin planning implementation of cCMV screening?**
 - Lab perspective: Would be helpful for NBS labs to test the different cCMV testing methods to determine which one is best and should be implemented
 - Funding and training is needed (pediatricians should receive training on how to best follow-up with diagnosed patients)
 - CDC aware of QCPT needs
 - Future potential joint work between APHL New Disorders Work Group and APHL Molecular Subcommittee to provide guidelines
 - APHL New Disorders Work Group has developed screening implementation toolkits
 - Would like the help of the CONECT Work Group to create a toolkit for cCMV
 - cCMV testing can include blood spots or hearing screens (depends on state NBS guidelines), which can be tricky
 - Collaboration between dried bloodspots and EHDl needed



Group Discussion

- **Question 1 (Continued): What support and resources do states/programs need as they begin planning implementation of cCMV screening?**
 - Encountering resistance from public health laboratories about why cCMV should be tested for prior to being added to the RUSP
 - Testing conducted through public health lab would be much easier and less expensive
 - One barrier to cCMV testing is the amount of blood needed but using less blood means losing sensitivity
 - A current cCMV testing kit using PCR method only requires a single punch but using less blood means losing significant sensitivity per contact at CDC
 - Kits are easier for labs to quickly implement than a lab-developed screening test but how well will this cCMV test kit work?
 - Waiting for sensitivity data for the cCMV testing kit



Group Discussion

- **Question 2: In what areas would more data, information, or collaboration be helpful in order to make informed decisions around universal screening for cCMV?**
 - What does collaboration between blood spot screening and hearing screening look like?
 - States may find it helpful to have guidelines about collaboration between both of these screenings
 - Perhaps more Federal involvement?
 - Possibly find non-traditional funding (e.g., foundation) that could augment the work
 - Reach out to Genetics Collaboratives to discuss collaboration



Future Outlook

- Would be great to have a place (e.g., SharePoint) where we can share information, data updates, articles, etc. with each other
- Discuss meeting more frequently to execute action items and/or establishing subgroups
- Create a space where information can be shared if meetings aren't feasible

- Clear that this model of coming together is valuable for all stakeholders
- Future meetings will highlight work around protocols and education, what is ready to be scaled

- The desire to expand this work needs to be met by funding support





The NBS Family Education Program

Navigate Newborn Screening
An Expecting Health Program

Education & Training

- ONLINE LEARNING CURRICULUMS
- VIDEOS
- MICROLEARNING WEBPAGES/BUNDLES

Awareness Campaigns

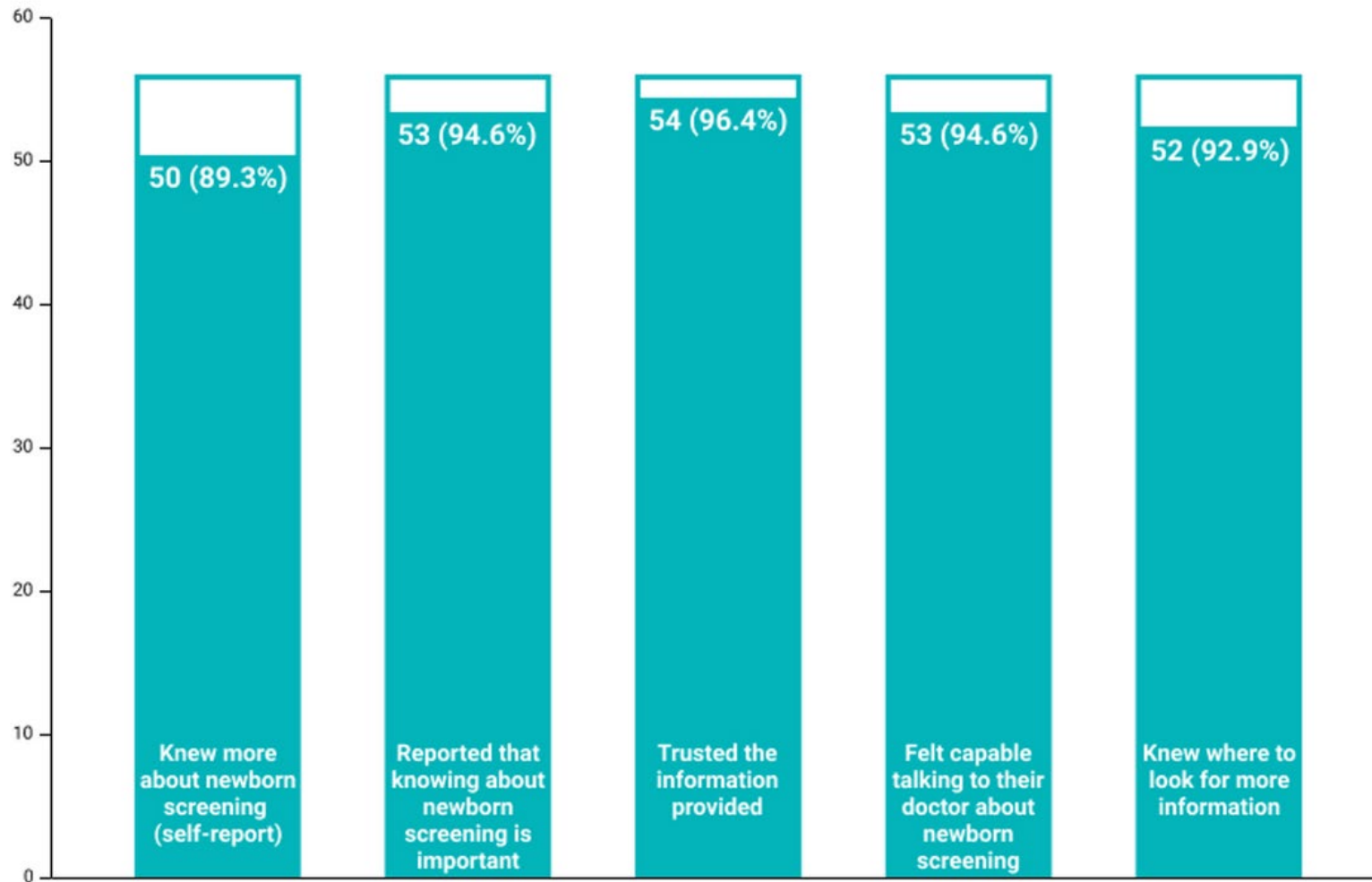
- *PRENATAL EDUCATION**
- *SOCIAL MEDIA**

Family Leadership

- NBS AMBASSADOR PROGRAM
- WEBINARS
- COMMUNITIES OF PRACTICE
- DISCUSSION GROUPS

EDUCATION IS MEETING FAMILIES WHERE THEY ARE

RESULTS FROM INITIAL PILOT PROGRAM AT LBJ



- **89%** or more reported **increases in awareness, knowledge, confidence and skill** to lead and advocate for newborn screening and their families (N=56).

WHAT WE HAVE SEEN



WE HAVE INCREASED
AWARENESS &
EDUCATION
OPPORTUNITIES, BUT IT
REQUIRES MULTIPLE
STRATEGIES FOR SUCCESS



BOTH ORGANIZATIONAL
AND INDIVIDUAL
PARTNERSHIPS ARE
CRITICAL TO MEET
FAMILIES WHERE THEY
ARE



INNOVATIVE ONLINE
& IN-PERSON
STRATEGIES ARE
REQUIRED TO REACH
FAMILIES IN MUC

Stay Connected.

Natasha Bonhomme

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MORE SUPPORT. MORE GUIDANCE. BETTER HEALTH

Questions for the Group

- How can we pull in more people who have experience into this group?
- While we have parents involved, would it be helpful to have a separate/concurrent/ sub group focused on family experiences/education/ awareness building efforts?
- For you, what would success look like for an effort like this?
- How would you like to be kept aware of what we discuss/ learn?
Updates to member organizations? Short information statements periodically? Other?

- If there is a group you think we should be working with please let me know!

